Billing Code 4165-15

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Health Resources and Services Administration

Agency Information Collection Activities: **Proposed Collection: Comment Request**

In compliance with the requirement for opportunity for public comment on proposed data collection projects (section 3506(c) (2) (A) of Title 44, United States Code, as amended by the Paperwork Reduction Act of 1995, Public Law 104-13), the Health Resources and Services Administration (HRSA) publishes periodic summaries of proposed projects being developed for submission to the Office of Management and Budget (OMB) under the Paperwork Reduction Act of 1995. To request more information on the proposed project or to obtain a copy of the data collection plans and draft instruments, email *paperwork@hrsa.gov* or call the HRSA Reports Clearance Officer at (301) 443-1984.

Comments are invited on: (a) the proposed collection of information for the proper performance of the functions of the Agency; (b) the accuracy of the Agency's estimate of the burden of the proposed collection of information; (c) ways to enhance the quality, utility, and clarity of the information to be collected; and (d) ways to minimize the burden of the collection of information on respondents, including through the use of automated collection techniques or other forms of information technology.

Proposed Project: Sickle Cell Disease Treatment Demonstration Program - Quality Improvement Data Collection for the Hemoglobinopathy Learning Collaborative (OMB No. 0915-xxxx) – [New]

Background: In response to the growing need for resources devoted to sickle cell disease and other hemoglobinopathies, the United States Congress, under Section 712 of the American Jobs Creation Act of 2004 (P.L. 108-357), authorized a demonstration program for the prevention and treatment of sickle cell disease (SCD) to be administered through the Bureau of Primary Health Care and the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA) in the U.S. Department of Health and Human Services. The program is known as the *Sickle Cell Disease Treatment Demonstration Program* (SCDTDP). The SCDTDP is designed to improve access to services for individuals with sickle cell disease, improve and expand patient and provider education, and improve and expand the continuity and coordination of service delivery for individuals with sickle cell disease and sickle cell trait.

To achieve the goals and objectives of the program, the Hemoglobinopathy Learning Collaborative (HLC) uses a process known as the Model for Improvement, a widely used approach to quality improvement (QI) in healthcare settings. The Model for Improvement utilizes a structured process that asks grantee teams to build on small tests of change in their healthcare setting, while providing monthly reporting on measurements. The proposed QI data collection and reporting system is an integral component of the HLC.

Purpose: The purpose of the proposed QI Data Collection strategy is to implement a system to monitor the progress of MCHB-funded activities in improving care and health outcomes for individuals living with sickle cell disease/trait and meeting the goals of the SCDTDP. Each grantee team will be asked to report on a core set of measures related to quality improvement for hemoglobinopathies. Through an evidence-based process, a bank of QI measures within each

grantee network has been developed to assess health care utilization of the SCD population as well as several aspects of the system of care.

The QI Data Collection strategy will provide an effective and efficient mechanism to do the following: (1) assess the services provided by grantees under the SCDTDP and monitor and drive improvement on quality measures; (2) collect, coordinate, and distribute data, best practices, and findings from network sites; (3) refine a common model protocol regarding the prevention and treatment of sickle cell disease; (4) examine/address barriers that individuals and families living with sickle cell disease face when accessing quality health care and health education; (5) evaluate the grantees' performance in meeting the objectives of the SCDTDP; and (6) provide HRSA/Congress information on the overall progress of the program.

Respondents: Grantees funded by HRSA under the SCDTDP will be the respondents for this data collection activity. Each month, SCDTDP teams will complete up to three data collection forms for 20 patients with SCD or sickle cell trait who were seen in their network that month. The Participant Profile form will collect demographic and basic health information. The Acute Care Visit and Ambulatory Care Visit forms will assess care in acute and ambulatory care settings, respectively.

All information will be collected via chart review. Data will be entered directly into a secure web-based data collection tool, called Research Electronic Data Capture (REDCap). The data entered into REDCap will be analyzed via a custom measurement generator that will calculate and export the QI measures for viewing by grantee teams and the National Coordinating Center.

The annual estimate of burden is as follows:

Questionnaires	Number of Respondents	Responses per Respondent	Total Responses	Hours per Response	Total Burden Hours
Participant Profile Form	9	240	2,160	.08	173
Acute Care Visit Form	9	240	2,160	.30	648
Ambulatory Care Visit Form	9	240	2,160	.30	648
Total	27		6,480		1,469

Email comments to *paperwork@hrsa.gov* or mail the HRSA Reports Clearance Officer, Room 10-29, Parklawn Building, 5600 Fishers Lane, Rockville, MD 20857. Written comments should be received within 60 days of this notice.

Dated: May 24, 2012

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[FR Doc. 2012-13124 Filed 05/30/2012 at 8:45 am; Publication Date: 05/31/2012]